

# Annual Report 2021





# Mission

The Division of Services for People with Disabilities (DSPD) supports and manages services for some of the most vulnerable people in Utah. Specialized teams orchestrate access to short-term and ongoing services. To do this, DSPD continuously engages with individuals, their families, national experts, service providers, and state leadership.

Services and supports should help an individual reach their vision of a good life, which includes their expressed goals, needs, and desires. Through partnership and research, DSPD continues to

enhance the service system. Significant effort is made to improve person-centered planning and increase the role of employment. An individualized approach to planning services and supports help the individual get both what is important to them and important for them. Employment has a positive impact on personal well-being as well as adding to the workforce that contributes to the Utah economy.

DSPD also oversees operations at the Utah State Developmental Center.



to promote opportunities  
and provide supports for  
**persons with disabilities to  
lead self-determined lives**

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# Director's Message

Angie Pinna



Fiscal year 2021 brought many exciting experiences alongside continuous public health challenges. DSPD carried on with efforts to keep individuals with disabilities safe and healthy. Division staff and service providers did not falter in their commitment to implementing system enhancements and creative solutions.

Legislative appropriations not only funded life saving service changes for individuals in-service, but also time limited services for individuals and families waiting for ongoing services. Funding helped individuals safely engage with the community and supplied flexibility for fluctuating service needs. Most noteworthy is the caregiver compensation program used by hundreds of individuals and families in Utah's disability community. We have heard so many stories from families about how this program provided refuge during such uncertainty.

Another significant achievement of fiscal year 2021 was progress with the *Christensen v. Miner* settlement agreement. During year two of the settlement agreement, DSPD transitioned 74 residents out of private intermediate care facilities (ICF) and into home and community-based services (HCBS). Additionally, hundreds of residents and potential residents received education about HCBS settings. Education efforts show individuals what services could look like, to help them decide if HCBS is something they want to explore. DSPD looks forward to continued engagement with ICF residents, and future transitions into HCBS.

The Settings Rule deadline is fast approaching. With less than two years left, all providers must be compliant by March 17, 2023. DSPD and the Department of Health worked closely with providers to help them implement business and service changes. I recognize that Settings Rule requirements are a huge shift for many providers, and am grateful that so many providers have already transformed their operations.

Thank you for your continued support and collaboration. I deeply appreciate the many voices that contribute to our success.

## Settings Rule Update

In light of the impact of COVID-19, CMS extended the HCBS final Settings Rule compliance deadline to March 17, 2023.



### Published Guidance

DSPD published several informational flyers to support understanding of the Settings Rule in the areas of employment, community inclusion and integration, rights restrictions, and more. We also published a guide to help providers continue to work towards compliance while meeting necessary COVID-19 related health and safety requirements.



### Heightened Scrutiny Review

DSPD and the Utah Department of Health began the process of compiling information, holding public comment meetings and periods, and submitting settings to the Centers for Medicare and Medicaid (CMS) for heightened scrutiny review. To validate compliance with the Settings Rule, DSPD used a virtual visit process to visit settings that completed remediation.



### Person-Centered Planning Tools

DSPD worked with the National Center on Advancing Person-Centered Practices and Systems (NCAPPS) to develop and publish the Person-Centered Planning foundational handbook for Support Coordinators. The handbook includes information on the philosophy of person-centered planning, tools to enhance the planning process, and clear expectations to ensure that the person directs their own plan as much as possible. DSPD also developed training videos and a webpage so that information about person-centered planning is available to anyone.

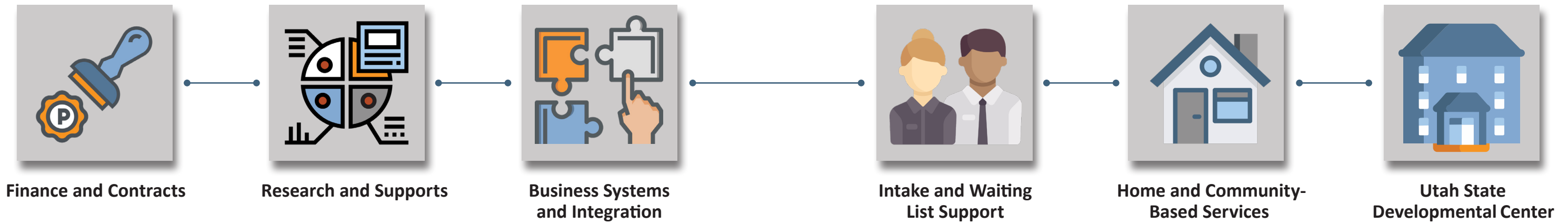
In August 2021, DSPD published a guided conversation tool named the Employment Pathway Tool. The Employment Pathway Tool helps a person make an informed choice about whether they want to be employed or not. DSPD developed and pilot tested the tool with support from the State Employment Leadership Network (SELN).



# The Division



DSPD provides support through home and community-based services (HCBS) and facility-based care. Five teams manage HCBS through state funding and Medicaid waivers. A team of clinical experts and experienced direct support professionals operate the developmental center.



6,206 People

served during FY 2021

74 Residents

of an ICF moved into HCBS



1,094 People

on the waiting list used Caregiver Compensation and Respite

1,183 People

on the waiting list received Personal Protective Equipment



# Appropriations



## Mandated Additional Needs

**\$** 6.0 M Ongoing General Fund

As part of the 1915(c) waiver approved by the Center for Medicare and Medicaid Services, DSPD must support changes in the health and safety needs of those already enrolled in waiver services. Each request for services (RFS) undergoes a comprehensive review of need by the RFS Committee before approval. This amount includes youth transitioning from DCFS/DJJS transfer funding.

## Limited Support Services

**\$** 258,200 Ongoing General Fund

The Limited Support Service model emphasizes prevention and encourages innovation. Offering some support sooner may help improve outcomes and reduce the need for out-of-home services.

## Public Health Response

**\$** 4.2 M One-time General Fund

Funding to maintain the system enhancements and provider relief implemented to address COVID-19. System enhancements prioritize the health and safety of everyone involved in the disability support system.

## CARES Act Funding

**\$** 7.4 M One-time Federal Funds

Utah used CARES Act money to offer respite and caregiver compensation to people on the waiting list. Enrolled caregivers received payment for assisting their family member with activities of daily living.

## CARES Act Funding



### Caregiver Compensation

Sept. – Dec. 2020	Apr. – June 2021
1,062 people	919 people



### Meals on Wheels

Sept. – Dec. 2020	Apr. – June 2021
160 people	145 people



### Personal Protective Equipment

Sept. – Dec. 2020
1,183 people



### Tablets and Other Expenses

Sept. – Dec. 2020
775 people

## Debbie's Testimonial

Many kiddos like my son are not always included in social opportunities. Through this amazing opportunity, I could organize those social interactions that he needs as a child. We visited places like Thanksgiving Point and All Stars in Draper. He played laser tag with groups he didn't know, and had the chance to feel a part of a team.

Caregiver compensation allows families, like ours, a way to help our children be apart of the world in which they live.

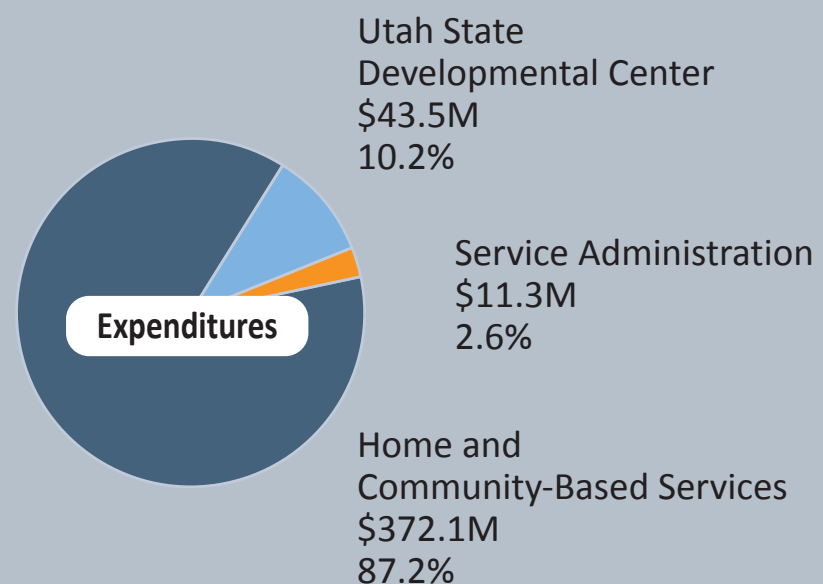
We can provide moments for them to **just be a kid!**



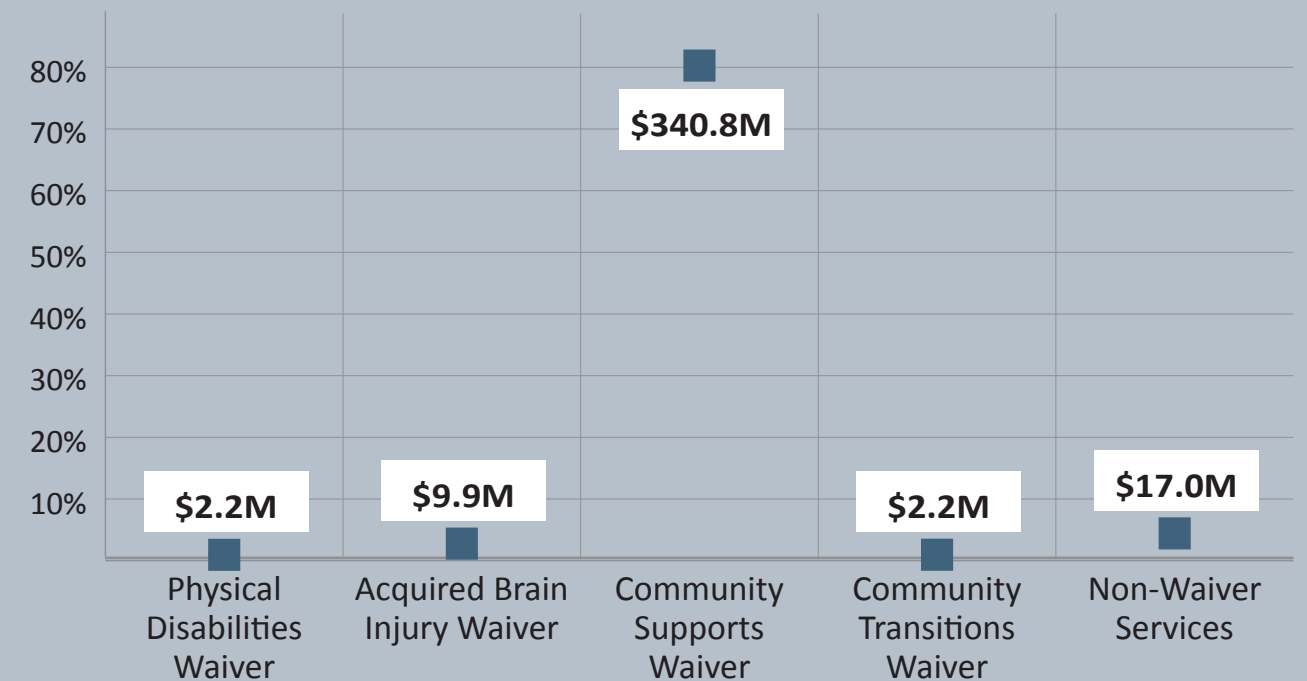
# Budget Overview

Each year DSPD uses the Federal Medical Assistance Percentage (FMAP) to calculate the percentage of federal matching funds received for every state dollar spent. All reported fiscal year 2021 dollar amounts use the fiscal year 2021 FMAP of 32.99%.

**\$426.9 M**  
FY 2021 Operating Budget



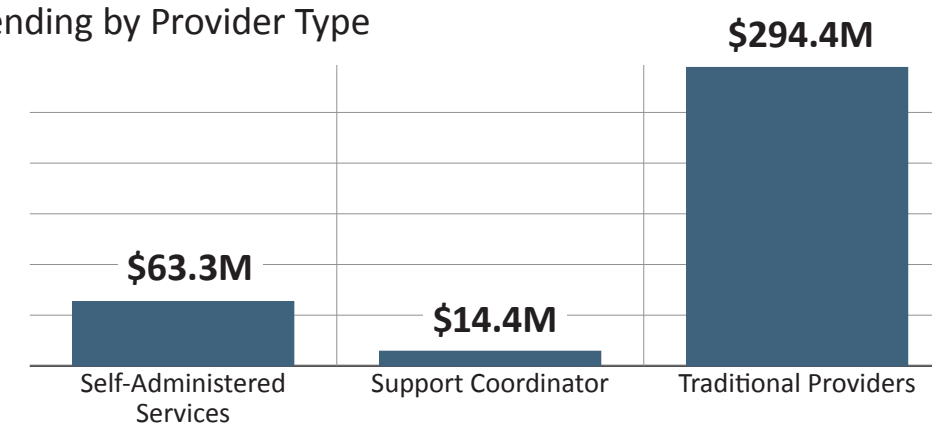
Home and Community-Based Services Spending



## Historical Budgets

FY 2020: \$404.7 million	FY 2017: \$298.0 million
FY 2019: \$364.8 million	FY 2016: \$270.9 million
FY 2018: \$327.7 million	FY 2015: \$243.8 million

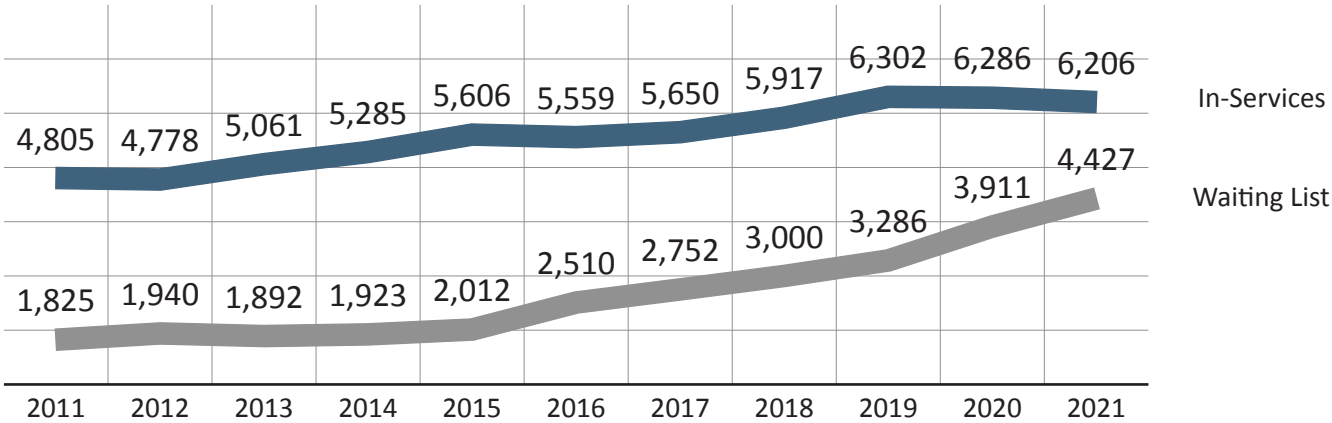
## Spending by Provider Type





# Historical Trends

Annual Count of People In-Services and Waiting for Services



## Jana's Testimonial

As a parent, the limited support program has been such a huge help to me. Before the program, my 19 year old daughter would spend most of her free time at home watching movies or listening to music. Since we have been able to hire friends and family to spend time with her, she has had many opportunities to get out more in the community, travel, learn new things, and bless the lives of those who work with her. Hanna has been to Disneyland, learned how to do her hair, been swimming many times, played games, learned to cook new things and so much more. As a working mom, it has been a huge help to me having someone to take her places and spend time with her. She has enjoyed it so much and it's been great to see her getting out of the house and living life! Thank you for providing these services for my sweet daughter.





# Waiting For Services

DSPD uses all available funds to provide services to as many eligible people as possible. Following fiscal year 2021 system changes, DSPD now offers enrollment based on most critical need for comprehensive services, and time spent waiting for people with limited support needs.

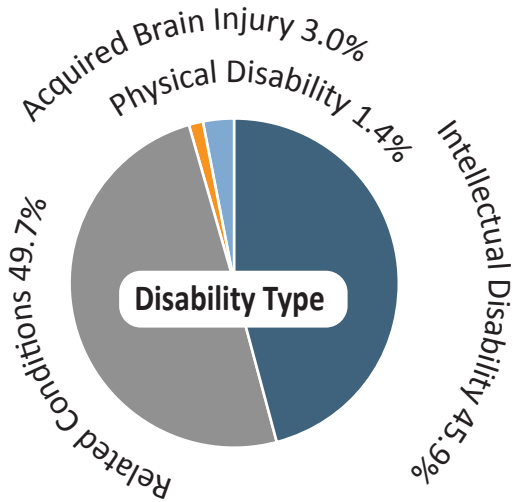
4,427  
people waiting

People waiting have an average age of 22.7 years, and wait an average of 5.7 years.

### Requested Services

Service	Percentage
Personal Assistance and Supported Living	38.2%
In-Home Support and Respite	53.4%
Residential Services	6.4%
Host Home and Professional Parent Services	2.0%
Day Supports	19.6%
Supported Employment	18.5%

Table does not add to 100%, because people can be waiting for more than one service.



# Short-Term Services

People may be eligible to receive one or more of the limited short-term services available while waiting for ongoing DSPD supports. Funding comes from a combination of ongoing and one-time appropriated general fund dollars allocated each fiscal year.

## Supported Work Independence

247 people served

SWI is designed to assist eligible persons, who are waiting for ongoing services, obtain and maintain competitive employment in an integrated setting, earning at least minimum wage.

## Caregiver Compensation and Respite

1,094 people served

In an effort to address caregiver burnout, DSPD can offer a person’s caregiver relief through limited, one-time respite services. During fiscal year 2021, DSPD used CARES Act and non-lapse funding to provide supported living and respite to families waiting for services.



# Home & Community-Based Services



Services support the person's choice to remain in their community.

Home and community-based services (HCBS) are an alternative to institutional care that provides habilitation services to people with disabilities.

HCBS providers are available throughout the state. DSPD offers two service models: provider agencies and self-administered services (SAS). The SAS model allows a person and their family to hire and train employees to provide support

6,206

people served during FY 2021

## Community Supports Waiver

5,767 people

A comprehensive, lifespan waiver that serves people with an intellectual disability or a related condition, who meet Intermediate Care Facility level of care.

## Acquired Brain Injury Waiver

158 people

Serves people 18 years or older with a brain injury, who meet Skilled Nursing Facility level of care.

## Physical Disabilities Waiver

90 people

Serves people 18 years or older with a physical disability that results in the functional loss of two or more limbs, who meet Skilled Nursing Facility level of care.

## Community Transitions Waiver

103 people

A comprehensive, lifespan waiver that serves people with an intellectual disability or a related condition, who move out of an Intermediate Care Facility.

## Limited Support Services

13 people

Lifespan assistance for people who meet DSPD eligibility requirements, and only need a small amount of assistance.

## Non-Medicaid Waiver Services

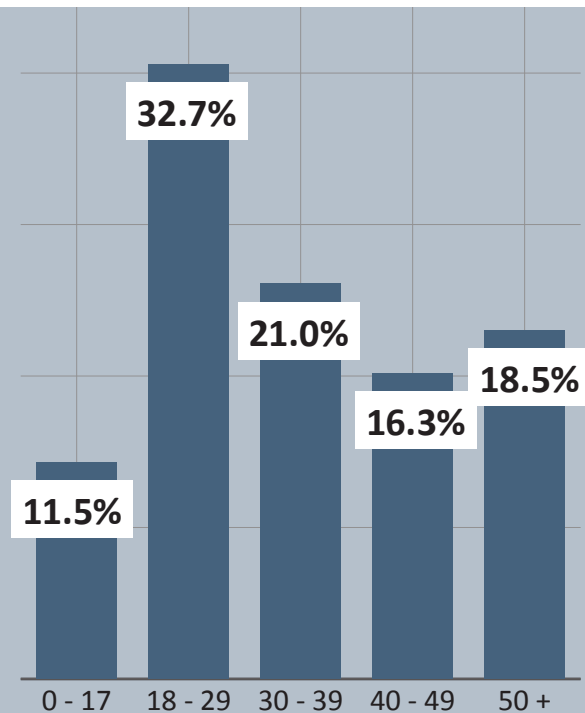
63 people

Lifespan assistance for people who meet DSPD eligibility requirements, but are not eligible for Medicaid funding.

Note: Twelve people were transitioning into services and not included in waiver counts.

# Demographics & Diagnoses

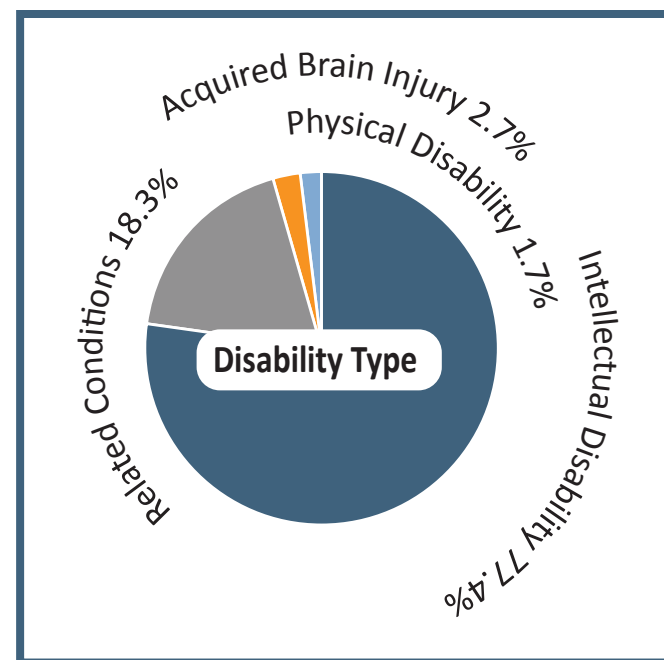
Age Range  
Average Age: 35.2 years



61.8%  
Male



38.2%  
Female



82.7% White

9.7% Hispanic or Latino/a/x

2.0% American Indian

2.1% Black or African American

1.9% Asian or Pacific Islander

1.6% Other

Eligibility for Division services requires that a person have a minimum of one qualifying diagnosis.

A qualifying diagnosis must give rise to mental or physical impairments that cause, at least, three substantial functional limitations in a major life activity, such as: self-care, language, mobility, capacity for independent living, and economic self-sufficiency.

The four disability types are broken down by the percentage of each qualifying diagnosis. Tables may not add to 100% due to rounding.

## Intellectual Disability

Diagnosis	Percentage
Mild	43.8%
Moderate	28.8%
Profound	9.1%
Severe	16.0%
Unspecified	3.5%

## Acquired Brain Injury

Diagnosis	Percentage
Concussion	18.1%
Head Injury	32.5%
Hemorrhage	15.0%
Laceration	5.0%
Other	35.0%
Stroke	3.1%

## Related Conditions

Diagnosis	Percentage
Autism	63.1%
Cerebral Palsy	13.5%
Chromosomal Abnormality	9.1%
Congenital Anomalies	1.4%
Epilepsy	3.7%
Other	7.0%
PDD	2.5%
Spina Bifida	1.4%

## Physical Disability

Diagnosis	Percentage
Cerebral Palsy	8.1%
Multiple Sclerosis	7.1%
Muscular Dystrophy	12.1%
Other	22.2%
Paraplegia	7.1%
Quadriplegia	47.5%



# New Service Recipients

A person's state budget is the amount of General Funds allocated for their services. The total budget includes the amount of federal matching funds received for waiver services.



## Appropriation Funding

The Legislature allocates funding to DSPD from the General Fund every year to support services.

The ICF Transition Program moved 74 people into HCBS with an average state budget of \$30,855 and an average total budget of \$95,487. DSPD provided limited support services to 13 people with an average state budget of \$5,299 and an average total budget of \$16,400.



## Attrition Funding

Every year some people leave DSPD services, and DSPD reinvests the money used for their services into the waiting list. Attrition funding allows DSPD to enroll people who qualify for emergency services and people court ordered into services.

The court ordered one person into services. Budgets typically have an average state budget of \$34,289, and an average total budget of \$113,719.



## Transfer Funding

DSPD collaborates with other divisions in the Department of Human Services (DHS) and ICFs to enroll people in HCBS.

Through DHS transfer funding, DSPD enrolled 50 people with an average state budget of \$23,697, and an average total budget of \$73,334. ICF transfer funds brought 13 people into HCBS with an average state budget of \$20,525, and an average total budget of \$63,520.

**151**  
people enrolled

# Contracted Providers

**177**

Provider companies offer direct support staff and structured programming designed to maintain health and safety in integrated, educational, and self-determined settings.

**57**

Support coordination companies are a network of Qualified Intellectual Disability Professionals. Support coordinators assist people and their families with coordination of care through Medicaid waiver services and other community resources.

**4**

Fiscal agents provide fiscal management services as part of the self-administered service model. Fiscal agents assist people and their support team with fulfilling employer requirements, including: hiring, payroll, and taxes.



# Service Categories

DSPD uses validated assessments, self-reporting, and provider experience to tailor a person-centered service plan (PCSP). Person-centered planning offers the person and their planning team choice from an array of community integrated programs in order to promote and foster self-determination. The resulting PCSP organizes available services to meet the person's needs, preferences, and goals by annually identifying

the person's changing strengths and priorities. Individual budgets within each service category vary based on need.

Category counts do not include individuals that did not bill a service during fiscal year 2021.

## Residential Support

2,265  
people

Average age: 40.5 years

Residential habilitation offers 24-hour support in supervised apartments and group homes as an alternative to institutional settings. Individualized assistance helps the person obtain and maintain independent living skills in their chosen community. Services that often accompany residential support, include: medication monitoring, behavior consultation, employment, and day support.

## Host Home & Professional Parent

611  
people

Average age: 32.0 years

Host family residential services offer a shared living experience for youth and adults, with exceptional care needs, who want a family environment, but cannot live with immediate family members. The host family provides assistance with independent living skills and supervision that helps the person engage in their community and avoid isolation.



## Supported Living

329  
people

Average age: 49.3 years

Multiple supported living options offer hourly, intermittent care for people who live in their own home. Services designed to maintain health and safety, and avoid isolation include: transportation, personal care, homemaking, chores, medication monitoring, advocacy, communication assistance, and other activities of daily living.

## In-Home Provider-Based

1,966  
people

Average age: 28.0 years

An enrolled person and their family can access respite, companion, homemaker, chore, and personal assistance through a contracted provider agency. The person and provider agency collaborate to design a service plan that maintains health and safety, and avoids isolation.

## In-Home Self-Administered

866  
people

Average age: 34.6 years

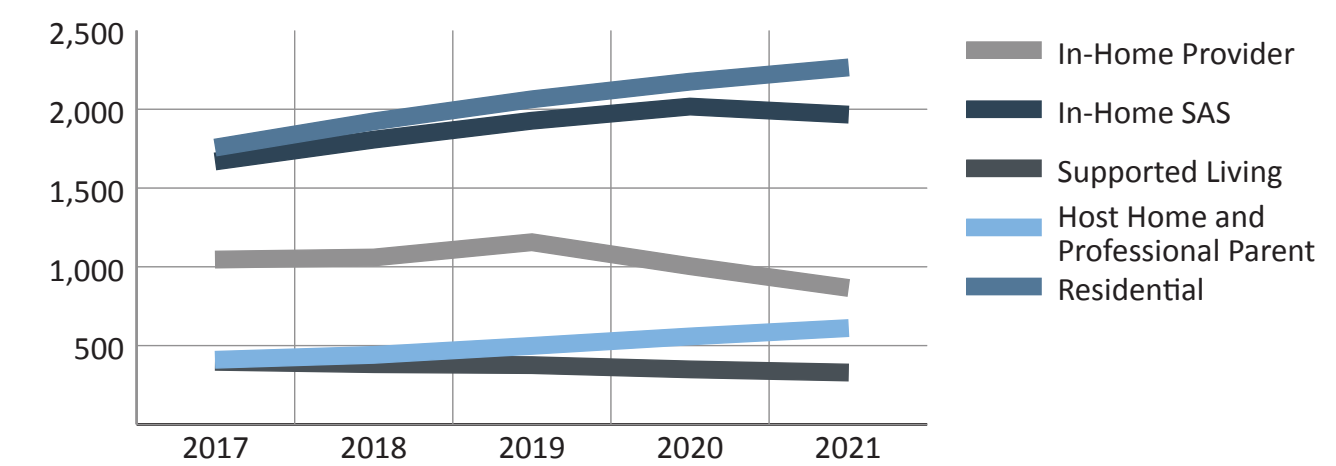
Self-Administered Services (SAS) allows a person and their family to employ their own direct service staff. SAS includes access to a fiscal management agent that provides payroll and budget management services. Waiver services offered under SAS include: respite, companion, homemaker, chore, and personal assistance.



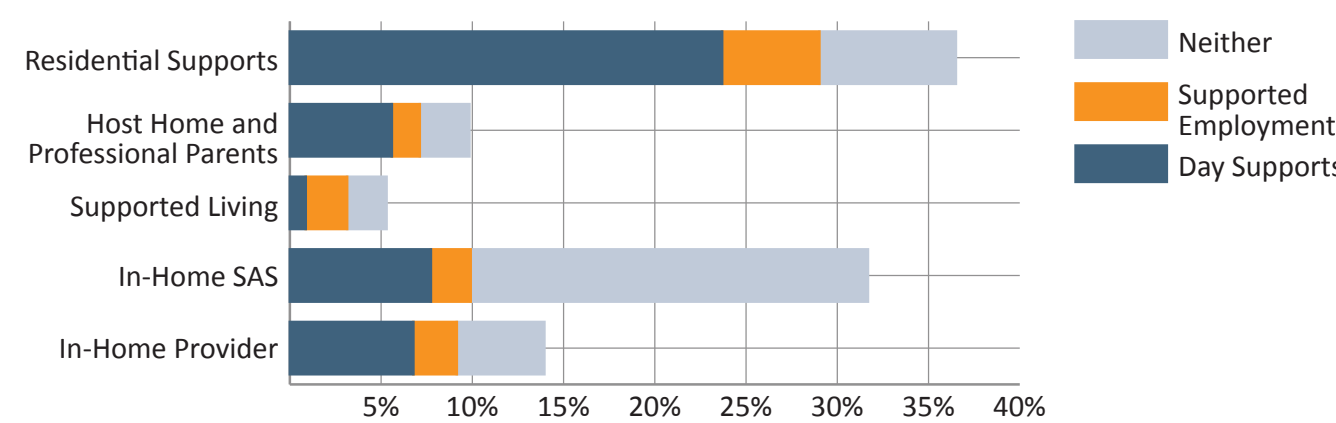
# Service Spending

DSPD may offer many similar services within a service category. Tracking category usage and spending helps DSPD evaluate service access and trends. Service data informs strategic planning and improvement efforts. The following graphs and data identify how many people use a category; how categories are combined with each other; and what spending looks like in each category.

Service Category Use: All Participant Counts by Fiscal Year



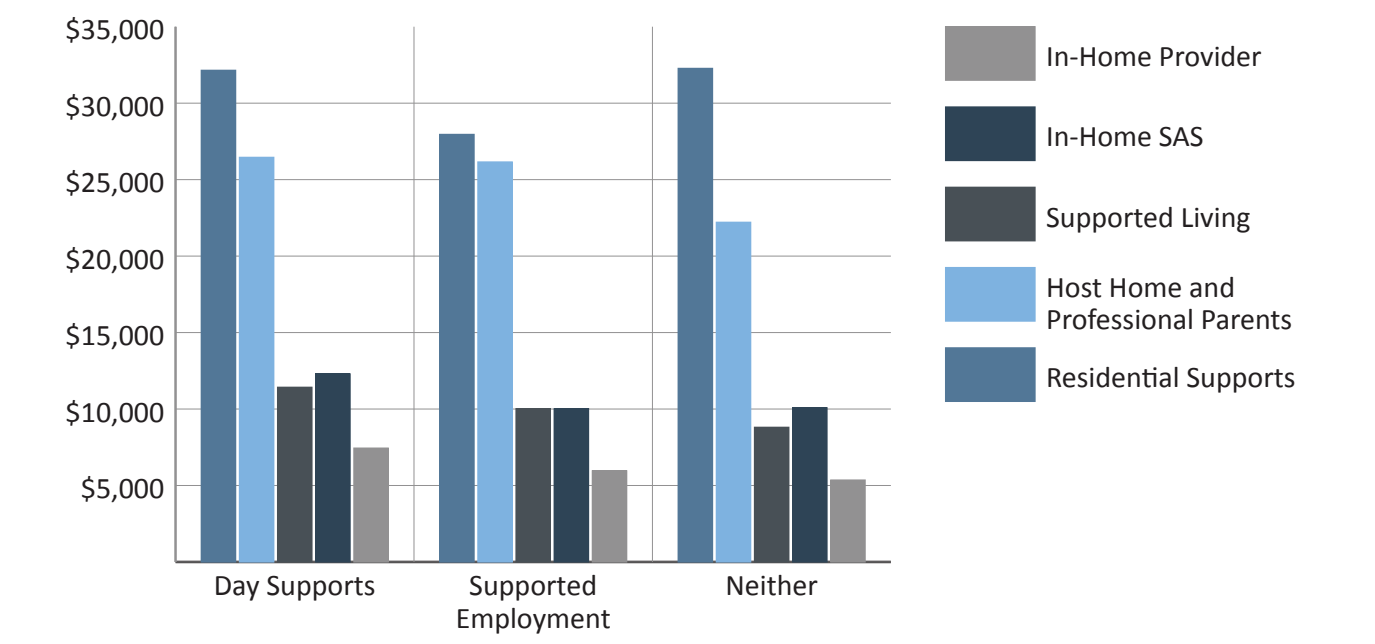
Service Category Use: Percentage of Participants in Combined Categories



Service Category Spending

Category	Average Annual Total Cost	Average Annual State Cost	Total Cost	Total State Cost
Residential Supports	\$95,674	\$31,561	\$216.7M	\$71.5M
Host Home and Professional Parents	\$76,499	\$25,236	\$46.7M	\$15.4M
Supported Living	\$29,580	\$9,758	\$9.7M	\$3.2M
In-Home Self-Administered Services	\$32,186	\$10,618	\$63.3M	\$20.9M
In-Home Provider-Based	\$19,613	\$6,470	\$17.0M	\$5.6M

Average Service Category State Cost with Combined Categories



# Day Activities

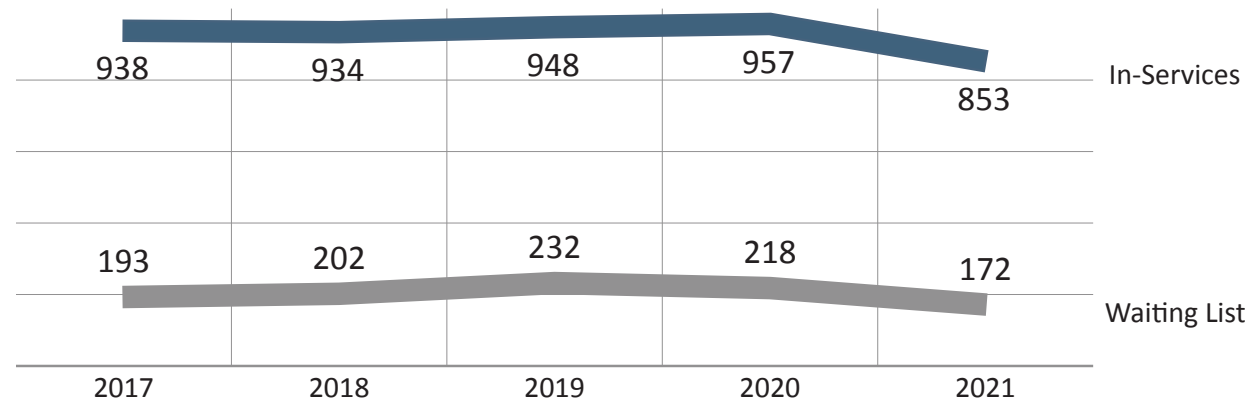


Committed to the Employment First initiative, DSPD recognizes the benefits of prioritizing meaningful, competitive employment opportunities for people enrolled in services.

Supported Employment Spending Five Year Trend

Fiscal Year	State Dollars	Total Dollars
2021	\$2.2M	\$6.0M
2020	\$2.6M	\$7.1M
2019	\$2.8M	\$8.0M
2018	\$2.7M	\$7.8M
2017	\$2.6M	\$7.4M

Supported Employment Historical Counts



## Day Support

Daytime supervision and support, in either an individual or group setting, designed to help develop and maintain habilitation skills, including: self-help, community living, and communication skills. Structured programs provide socialization, skill building, and leisure activities. During fiscal year 2021, 2,771 people with an average age of 32.0 years used day support.



## Supported Employment

Supported employment provides assistance for adults who want to obtain, maintain, and advance in competitive integrated employment and entrepreneurship paying at least minimum wage, or in self-contained business locations. A job coach or co-worker supports either an individual or group. Employment support offers the flexibility to customize work hours and setting in order to follow the person's interests and achieve the person's goals. During fiscal year 2021, 853 people with an average age of 40.5 years used supported employment.

## Supported Work Independence

SWI provides skill development and job coaching to adults waiting for ongoing services.

53%

Employed

\$8.34

Average Hourly Wage

14.1

Average Hours Worked Per Week



# Utah State Developmental Center

Dedicated to providing evidence-based resources.

63.4%  
Male



36.7%  
Female

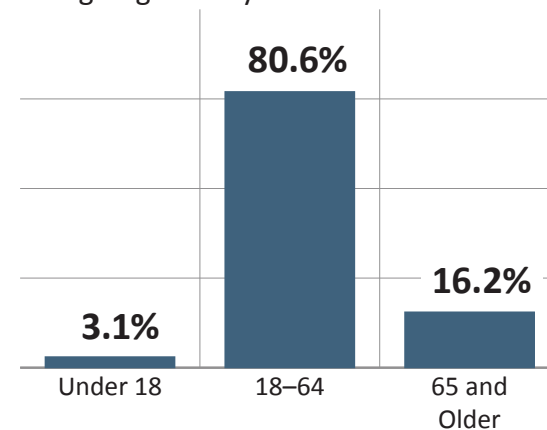
USDC serves all ages in a comprehensive residential setting. On-site services include: habilitation, medical, dental, employment, and recreation. Dormitory style living matches four to six people as roommates who share common areas. Staff assist with grocery shopping, cooking, and cleaning. During fiscal year 2021, USDC admitted 8 people and discharged 5 people.

USDC typically offers respite support for people enrolled in DSPD services. Families report that this valuable service supports continued caregiving at home. COVID-19, however, added new challenges to supporting the health and safety of residents and staff. Risk of spreading the virus meant that USDC could not offer respite during fiscal year 2021.

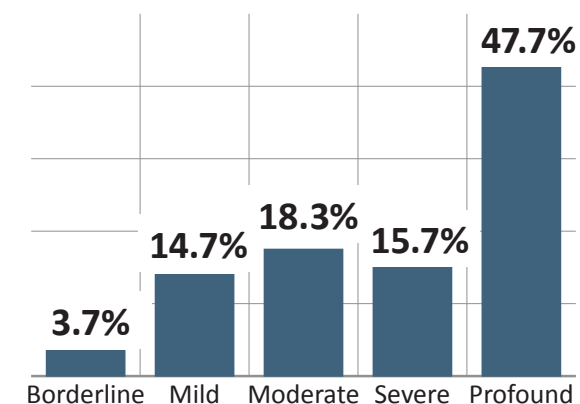
191  
people served

## Age Range

Average Age: 47.3 years



## Intellectual Disability



74 Residents  
moved into HCBS



# ICF Transition Program

The ICF Transition Program provides an opportunity for individuals who live in an intermediate care facility to move into a home and community-based setting.

As part of the *Christensen v. Miner* settlement, the program will move 250 individuals who want to live in the community from an ICF into HCBS between fiscal years 2020 and 2024. Program Specialists educate ICF residents and individuals requesting admission to an ICF about HCBS. Interested ICF residents can visit HCBS providers and service sites to gain a better understanding of available services.

80  
potential residents  
received HCBS education

500  
residents received  
HCBS education





## Additional Information

Visit the [DSPD website](#) for more information about any of the topics in the 2021 Annual Report.

Visit the [USDC website](#) for more information about admission and services.

utah department of  
**human services**  
SERVICES FOR PEOPLE WITH DISABILITIES